Consumer Advisory Group Meeting
May 29, 2013 10-11:30a

Name	Organization
Alec Ziss	CapeCare
Kathleen Donaher	Regis College
Eileen Elias	JBS International
Lisa Fenichel	eHealth Consumer Advocate
Georgia Simpson May	MA Dept of Public Health
Support Staff	Massachusetts eHealth Collaborative
Micky Tripathi	Massachusetts eHealth Collaborative
Mark Belanger	Massachusetts eHealth Collaborative
Erich Schatzlein	Massachusetts eHealth Collaborative
Jennifer Monahan	Massachusetts eHealth Collaborative

Review of Materials and Discussion

Project Updates

- Mass HIway Phase 2 Timeline Update (Slide 2)
    - The group reviewed the Phase 2 timeline. See slide for full timeline updates. Testing for the Syndromic Surveillance Node and the Children's Behavioral Health (CBHI) Node has been completed and is expected to go into production later this summer. HIway Phase 2 services are still planned for rollout between October 2013 and March 2014.
    - Question: What does "completed" mean for the public health nodes?
        - Answer: The public health nodes are an addressee on the HIway. Users can now send information via the HIway instead of the current submitting processes. The goal is to consolidate the submission process for public health initiatives.
    - Question: With the shortage of child psychiatrists, what does it mean for behavioral health node in terms of information and care?
        - Answer: The Children's Behavioral Health Initiative is in response to the "Rosie D" court case which was brought against the state for not living up to state responsibilities for taking care of children with mental health issues.
        - More information will be distributed to the Advisory Group to provide a better understanding of the Children's Behavioral Health Initiative.
    - Question: Will there be a process for monitoring or evaluating if the public health notes are being used and if participants are finding them useful?
        - Answer: The HIway is required to report back to CMS on how the funding is being used. An annual program evaluation is also required. The American Recovery and Reinvestment Act (ARRA) contains a provision that each state

must spend 2% of the grant money to evaluate progress in 2012 and 2013. MeHI has the responsibility to produce report this year which needed to be completed by May or June of this year. Next year, the report is due by quarter one of 2014 for the calendar year 2013.

- Question: Is there any overlap between the two public health node items as far as data being sent? Will somebody be looking into co-morbidity or co-occurring items, like when a child has a behavior health disorder but may have other challenges?
  - Answer: This is likely something that public health may be thinking about. From the HIway perspective, the goal is simply to transport the data from the provider to the public health agencies. What the public health agencies do with the data is the responsibility of the organization. The HIway does not keep clinical information and evaluating data is not part of HIway responsibilities.
- Question: Does "behavior health" mean both psychiatric disorders and substance abuse?
  - Answer: Not sure if the behavioral health program includes substance abuse. Substance abuse brings in additional privacy protections.

Phase 2 Technical Design Under Consideration

- Key Issues Review (Slide 4) – The group reviewed the proposed approach for the discussion material to be presented. EOHHS and Orion have begun scoping for the technical design of Phase 2 services, and the Advisory Group was asked to provide feedback on the discussion items to follow. The group also plans to discuss current approaches for Phase 1 consent
- MA HIway Phase 2 Consent Approach - Patient consent on both sides of transaction (Slide 5)
  - The HIway will be moving from a push transaction approach in Phase 1, to a provider query/retrieve approach in Phase 2. Consent will happen on both sides of the transaction for query/retrieve requests.
  - The group reviewed the consent process for the example patient provided on the slide.
  - The Relationship Listing Service (RLS) allows a provider to view where a patient has received care. No clinical information is available, only demographic information is available on the patient.
  - Patient gives consent for a provider to send information to the RLS to show where the patient has received care. The data holding organization sends the information via automated Health Level Seven (HL7) admission, discharge, transfer (ADT) messages, which contain consent indications as given by the patient.
    - Question: Does this assume that the provider has access to the system. Many providers in Cape Cod locations are not on the HIway.
      - Answer: Yes, it implies the organization is on the HIway.
      - Comment: Micky will be meeting with Cape Cod Healthcare to discuss future HIE plans. There may be some progress coming soon for HIE development and integration.

        - Question: Can we add behavioral health complexities to the discussion of the test patient presented on the slide?
            - Answer: It may be best to add complexities after the base case of the consent process is explained and then stress test it with more complex scenarios once everyone understands the base case
            - Comment: The CBHI and other public health reporting are specific public health reporting requirement programs that are in place today. There are no consent issues with these programs now, and the HIway is only a facilitation method for these requirements already in place.
    - A second consent control is consent to view the information. Any organization who wants to view information via the HIway, must obtain consent from the patient as well.
        - Question: At the HIT Council meetings, organizations gave narratives on the consent processes they are using now for Phase 1 services. It seems the consent processes are not uniform and are very generic. Would Phase 2 consent be similar in the approach, or would there be more a uniform approach to consent policies?
            - Answer: This will be a policy question to be considered in Phase 2 planning. There is a greater need for a more formalized and uniform consent policy for phase 2.
        - Question: Will Phase 1 consent policies need to change once Phase 2 is incorporated?
            - Answer: Phase 1 services stand apart from Phase 2 services and organizations can stay on Phase 1 without adopting Phase 2. The consents for each phase must remain distinct and separate. Phase 1 consent would not morph for Phase 2. The Phase 2 consent will require greater uniformity. Phase 1 services are identical in nature to faxing, phone, and mail communication for sharing patient information and therefore the consent mirrors current processes already in place for sharing information in those formats. Organizations do not want to give the patient a separate form for the HIway services as it may imply that there is a difference in the way information is shared.
            - Comment: Patients are never given a form to sign for consent about sharing information, and therefore have not expressed permission for a provider to share information via phone or fax.
                - Response: Notices do vary, but practices provide consent to treat forms that explain that information will be shared with other providers involved in patient care. The notices do not indicate specific modes that will be used for sharing information.
            - Comment: When you conceptualize both faxing and electronic methods of sharing information, they are not the same. The process is different,

and the likelihood for systematic error may be greater for electronic transmission.
        - Response: The same potential errors are involved in faxing as sending electronic. Addressees can be entered incorrectly in both methods.
    - Question: How are we adding value when using electronic transmission?
        - Comment: The HIway does not store any information. The HIway is encrypted end to end and the transactions are auditable unlike what is available when using fax, phone, or mail services.
    - Comment: Concern is that the point to point contact with a fax is limited, but the HIway opens up the potential for other points.
        - Response: Faxing is also done electronically now in most EHR systems. There is still a potential to incorrectly enter fax number(s). This is the same risk on the Phase 1 HIway services when addressing transactions.
- How it could work: Data holder publishes patient/entity relationship to RLS (Slide 6)
    - The group reviewed the consent process and RLS view process for the test patient example on the slide.
    - The HIway receives ADT messages from organizations and populates the RLS. If the ADT does not have a "yes" consent, the information would not be available on the RLS
    - Question: A medical record can contain information about where a patient is referred to. If a referral is made to a substance abuse provider, is that information confidential?
        - Answer: The patient relationship information published to the HIway only shows what organization has records on the patient. It would be different if a substance abuse provider participated in the HIway. The substance abuse provider could not publish information to the RLS.
            - Question: What would the organization say if the patient doesn't consent to sharing information?
                - Answer: A substance abuse organization would likely tell the patient not to consent due to the nature of treatment.
    - Question: Aren't the contents of the medical record dictated by Meaningful Use to contain a specific set of information? If there is something built in to the interface to be more cautious about certain information?
        - Answer: The ADT messages are only to provide information that an encounter has happened. By definition, the ADT will contain very little or no clinical information. Some clinical information, such as reason for visit or chief complaint may exist in some message. By design, the HIway will "dump" any clinical information that is beyond the basic demographic fields.

- Comment: Wouldn't department indication such as Radiology or Emergency Room be available? This could be considered clinical since it provides information to the type of treatment the patient has received.
    - Answer: The HIway would only show the organization name as a whole, not department, for where the treatment occurred. The message is only used to confirm that a relationship exists at an organization.
- Question: What about things like medication reconciliation which is important for patient safety. Would that vary by organization?
    - Answer: The next set of slides that this is just about identifying where records are from. The next discussion will be about how a provider requests a record once it is located on the RLS. The record that is sent may be used for medication reconciliation, but that is between the two organizations that are sharing information. The HIway is never a participant in the details of the transaction and does not store any of the information.

- There is an idea of having a "memory list toggle." Patient can change their mind on consent to share information. If the patient changes their mind and consent is changed to "no," and information related to that relationship would be deleted. If consent is changed again to "yes," the relationship would be re-established from that point forward. No historical data available before consent switched to "yes."
    - The assumption is that EHRs can capture a binary consent for "yes" or "no" and send the flag in an ADT messages to the HIway. Currently, there are no standards that require EHRs to have to capability to capture and send this information.
- Question: What exact information is the HIway receiving when consent is given by the patient?
    - Answer: An ADT message contains a limited set of demographic data from the PV1 segment (patient visit segment). The segment basically contains the patient name, medical record number, address, phone number, and the location message came from which would be the HIway participant entity name.
        - Question: Is the medical record number the organization's medical record number?
            - Answer: Yes, it would be the number from the organization.
        - Question: No clinical information is contained?
            - Answer: By design, no clinical information would be present.
            - Comment: The State has the same concern about clinical data, because the state does not want clinical data being available either.

- How it could work: Data requestor views patient/entity relationship within RLS (Slide 7)

- The example patient is now at another location that may want to view information about the patient. The patient provides consent for the organization to search the RLS and potentially retrieve information from another organization. All RLS request information is logged for audit purposes.
- Question: This is a model of how the process *could* work?
  - Answer: Yes. The design is not finalized at this time, but is the current preferred approach.
- Question: What would prevent a data requestor from looking up a patient without having obtained consent? Consent is often very broad, and some providers may just look without explicit patient consent.
  - Answer: A provider using the RLS without obtaining consent from the patient would be lying by viewing information. The request to view contains a consent flag, and if the consent has not been obtained, the provider is not authorized to look up the patient information.
  - Question: Does "consent" imply written consent?
    - Response: The answer is up to be defined as part of the planning phases.
    - Comment: A separate example for consent is what is used today for ePrescribing. Surescripts requires consent from a patient for the provider to use the service, which is sent in the e-Prescribing message. Most practices do not have a separate consent form for a patient to sign providing permission to use Surescripts. Most providers use the implication that if a patient wants a medication, then consent is given. This type of approach may be able to be used for RLS searches.
  - Question: What is the difference between hiding and deleting information?
    - Answer: There is a need to maintain some information for audit purposes. If consent is not given or is taken away, all information is gone from view on the RLS. However, there needs to be a trail of record for when patient consent preferences were changed.
    - Question: What about for legal matters like police investigations or a malpractice matter?
      - Answer: Those matters would go through the same type of audit process.

- How it could work: Data requestor requests patient record – Data holder sends patient record (Slide 8)
  - Question: The slide clearly states "send patient record." Does that mean the demographic information is being sent, or is that for clinical information?
    - Answer: This is where the record can actually be sent. The provider requesting information on the patient has determined the location of a record, the patient has given consent, and the request is sent to the other organization. The data holding organization authenticates the request, and decides how to respond.

            - Question: Does that mean that the Massachusetts eHealth Collaborative could view the clinical information?
                - Answer: No, absolutely not. This is a point to point transaction between the data requesting entity and the data holding entity that is encrypted end-to-end in the transmission process and nothing stored in the middle.
    - Federal standards are emerging for attaching an actual consent document. An example would be a PDF document of a signed consent form. This may help the data holding organization feel comfortable sending patient records, especially if the requesting organization is not a well known trading partner.
    - Question: Can the patient say "yes" or "no" to different organizations for record sharing and record retrieval?
        - Answer: Yes, the patient can determine which organizations can send and/or request record information.
    - If a patient can direct a provider where to retrieve records from, an organization does not need to use the RLS to find the records because the patient has indicated location. The organization can simply request the records using the HIway, without using the RLS first.
- How it could work: Patient Options (Slide 9)
    - The slide adds options for the patient to potentially participate in the HIway. Patient may be able to receive a Direct address, which would authenticate a patient identity and give providers the opportunity to send the patient encrypted messages or records. The patient would also be able to view RLS details and obtain audit information.
    - The patient may also have an opportunity to request notifications for changes made to the RLS data available on that patient.
- How it could work: Provider Subscription to Changes in Patient RLS (Slide 10)
    - Subscription notifications could be helpful for providers to keep track of patients. This may be applicable for Patient Centered Medical Home (PCMH) tracking of referrals. The RLS notification could indicate that a patient was seen by a specialist that the patient was referred to. This could reduce staff requirements for following-up on patient referrals.
        - Question: Are the notifications something the provider would opt-in to, or would the information just come in?
            - Answer: The patient must provide consent for these types of RLS notifications, and the provider would need to request the subscription to receive the notifications.
            - Comment: The consent issues are very complicated and may make this idea impossible or improbable. There are questions about how to filter and how often RLS information should be sent via notification. Another question would be how to turn off the notifications if a patient leaves a practice or no longer wants to the provider to receive notifications?

        - Comment: Providers may get fatigue and ignore the messages if the notifications are too frequent or cannot be filtered correctly.
    - Comment: It sounds like providers are going to be overloaded with information checking procedures for consents and not necessarily receiving information that is helpful about the patient. There should be concern about the time constraints and the effect on patients receiving care after the amount of time taken up with the other requirements. The requirements may get in the way of providing timely and quality care to patients.

- Question: Did the Legal and Policy Advisory Group work on consent approach last year. Are these ideas and discussions shaped around the work that was done by the group?
    - Answer: The Legal and Policy Advisory group did work on Phase 1 consent information, but that will not apply to Phase 2. There was also a Legal & Policy group that was a part of the MeHI workgroups which developed a consent approach for an older HIE model which included a repository. The work done at that time is out of date because the previous HIE model used a very different approach.
    - The Legal & Policy framework document will be provided to the Consumer Advisory Group for reference.
- Comment: Most of the literature on the success of HIEs is measured by number of transactions. The HIway should be more cautious of the types of transactions, rather than just the number. Otherwise, the information could just be "garbage in, garbage out."
- Comment: Massachusetts is an Opt-In state, which the more consumer protective and engaged approach for HIEs. Someone acting purposefully has a much better chance of making the HIE useful.
- Comment: Most successful HIEs have an Opt-Out structure, is that accurate?
    - Answer: There should be voluntary participation. The HIway accomplishes this because the patient is given control over who shares information and who is able to view information.
    - Comment: "opt-in" will allow providers to get closer to the patient engagement process rather than an "opt-out" process.

- The Advisory Group requested more information on: The Children's Behavioral Health Initiative (CBHI) and HIE Program Evaluation. The Advisory Group also requested to review the document produced by the Legal & Policy Advisory group.

Next steps

- Key points and recommendations synthesized and provided back to Advisory Group for final comments

- Presentation materials and notes to be posted to EOHHS website
- Next Advisory Group Meeting – July 24, 10:00-11:30 am.
    - Conference call – number to be updated in invitation
- HIT Council – July 1, 2013, 3:30-5:00 One Ashburton Place, 21st Floor
    - Question: Will there be any presentation of what the Advisory Groups discussed this week?
        - Answer: Reflections from the Advisory Groups will be on the agenda for discussion. There may not be much to report to the HIT council meeting this time because the Advisory Groups have not have much time to reflect on materials. The next meeting may be more of an update on the Advisory Group discussions.
    - Comment: The Advisory Groups are not getting a chance to see the discussion materials that will be brought to the HIT Council. The group members may have items to add, subtract, or clarify before the materials are presented.
        - Response: Synthesis from the meetings is distributed to the Advisory Groups for review. The materials prepared for the HIT Council meetings are coming directly from the synthesis of the Advisory Group meetings. Providing the HIT Council slides to the Advisory Group for review in advance would not be possible because they are generated too short in advance of the meeting.
            - Question: Does the Advisory Group get the slides that are presented at the HIT Council?
                - Answer: The slides are not sent to the Advisory Group to review in advance. The slides are available on the EOHHS website.
    - Comment: The Advisory Group does not use a meeting minutes approval process.
        - Response: The Advisory Group does use a minutes approval process. The minutes are distributed to the Advisory Group members for review, comments, and feedback. There is not a formalized approval process at the beginning of each meeting because too much time would pass in-between meetings and synthesis would not be ready for the HIT Council meetings.
        - Comment: The meeting minutes are too homogenous. I think we (the Advisory Group) are much more effective than that. We are much more thoughtful. The minutes are broadly stroked and the individual topics are not always detailed out.

HIT Council meeting schedule, presentations, and minutes may be found at
http://www.mass.gov/eohhs/gov/commissions-and-initiatives/masshiway/hit-council-meetings.html